Tribal Leaders Diabetes Committee

Meeting Summary

April 27–28, 2006

Reno, Nevada

(Approved September 15, 2006)

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Contents

TLDC Members Present

Dr. Kelly Acton (Federal co-chair)

Anthony Addison Sr. (Billings Area)

Carlton Albert Sr. (Albuquerque Area)

Alice Benali (Navajo Area)

Dr. Judy Goforth Parker (Oklahoma City Area)

Deborah Hall-Thompson (Aberdeen Area)

Linda Holt (Portland Area)

Rosemary Nelson (California Area)

Roberta Nutumya (Phoenix Area)

Buford Rolin (Tribal co-chair; Nashville Area)

Wavalene Saunders (Tucson Area)

H. Sally Smith (Alaska Area)

Others in Attendance

Karen Benally

Stacy Bohlen

Lisa Bumpus

Althea Cajero

Helen Canterbury

Lemyra DeBruyn

Carolee Dodge Francis

Joe Finkbonner

Antonia Hall

Hank Haskie

Marilyn Joe

Jefferson Keel

Gale Marshall

Robert Nakai

Kim Neiman

Anthia Nickerson

Gordon Quam

Jim Roberts

Bernice Sage

Benjamin Smith

Geoff Strommer

Nelson White Sr.

Phyllis Wolfe

Abbreviations

ADA ..... American Diabetes Association
AHA ..... American Heart Association
AI/AN ..... American Indian and Alaska Native
ADC ..... Area Diabetes Consultant
CDC ..... Centers for Disease Control and Prevention
CMO ..... Chief Medical Officer
CMS ..... Centers for Medicare and Medicaid Services
CPRS ..... Computerized Patient Record System
CRS ..... Clinical Reporting System
DDTP ..... Division of Diabetes Treatment and Prevention
DHHS ..... Department of Health and Human Services
DPP ..... Diabetes Prevention Program
DST ..... Direct Service Tribes
DSTAC ..... Direct Service Tribes Advisory Committee
EHR ..... Electronic Health Record
FACA ..... Federal Advisory Committee Act
FY ..... fiscal year
GPRA ..... Government Performance and Accountability Act
GUI ..... graphical user interface
HIPPA ..... Health Insurance Portability and Accountability Act
HPDP ..... Health Promotion and Disease Prevention
HRSA ..... Health Resources and Services Administration
IHCIA ..... Indian Health Care Improvement Act
IHS ..... Indian Health Service
INMED ..... Indians Into Medicine Program
IRB ..... Institutional Review Board
IT ..... information technology
ITU ..... Indian Health Service, Tribal, and urban Indian programs
JDRF ..... Juvenile Diabetes Research Foundation
NCAI ..... National Congress of American Indians
NDWP ..... Native Diabetes Wellness Program
NIH ..... National Institutes of Health
NIHB ..... National Indian Health Board
NPAIHB ..... Northwest Portland Area Indian Health Board

Abbreviations (continued)

OIG ..... Office of Inspector General
OIT ..... Office of Information Technology
OMB ..... Office of Management and Budget
PART ..... Program Assessment Rating Tool
RFA ..... Requests for application
RPMS ..... Resource and Patient Management System
SAMHSA ..... Substance Abuse and Mental Health Services Administration
SCHIP ..... State Children's Health Insurance Program
SDPI ..... Special Diabetes Program for Indians
TLDC ..... Tribal Leaders Diabetes Committee
TSGAC ..... Tribal Self-Governance Advisory Committee
UN ..... United Nations
USET ..... United South and Eastern Tribes
VA ..... Veterans Affairs

Summary of Motions

- Motion carried to approve the TLDC meeting agenda for April 27–28, 2006. (Page 9)
- Motion carried to work in partnership with the ADA on the SDPI reauthorization, and include the ADA advocacy packet on the next TLDC meeting agenda. (Page 12)
- Motion carried for the TLDC to attend meetings on the SDPI reauthorization in Washington, DC: Tribal leaders meeting on June 13, 2006, and stakeholders meeting on June 14, 2006. (Page 12)
- Motion carried to share Dr. LeMyra DeBruyn's TLDC presentation and the *Eagle Books* with the NDEP. (Page 17)
- Motion carried to adopt the TLDC meeting summary from February 15–16, 2006. (Page 21)

Summary of Action Items

Action Item	Timeline	Person Responsible	Notes
Dr. Roubideaux will provide the TLDC with a draft of the SDPI advocacy kit prior to the next TLDC meeting for their review and input. (Page 12)	September 14–15, 2006	Dr. Yvette Roubideaux and IHS DDTP	Dr. Acton will contact Dr. Roubideaux.
The IHS DDTP will provide copies of the long and short versions of the best practices for each TLDC member at the next TLDC meeting. (Page 14)	September 14–15, 2006	IHS DDTP	Althea Tortalita-Cajero will obtain copies from Dr. Kelly Moore for the TLDC meeting packet.
The IHS DGO will provide the IHS DDTP with a list of all grantees with excessive carryover balances. The IHS DDTP will share this list with the TLDC at the next TLDC meeting. (Page 15)	September 14–15, 2006	IHS DDTP and IHS DGO	Dr. Acton will contact Lois Hodge and Michelle Bulls.
The TLDC will submit a letter to Dr. Grim that outlines TLDC concerns on grants issues, particularly the need for budget flexibility. (Page 16)	Complete	TLDC	—
The third (next) TLDC meeting will be held September 14–15, 2006, in Washington, DC. The agenda should include an update on the IHS chronic disease management initiative. (Pages 21)	September 14–15, 2006	TLDC	Dr. Acton will contact Dr. Reidhead, who may be unable to attend the meeting.

Summary of action items continued on next page.

Summary of Action Items (continued)

Action Item	Timeline	Person Responsible	Notes
The fourth TLDC meeting will be held December 7–8, 2006, in San Francisco. The meeting agenda should include a presentation from Dawn Phillips. (Page 21)	December 7–8, 2006	TLDC	—
The IHS DDTP needs to provide a schedule of upcoming TLDC meeting dates to Dr. Grim's office. (Page 22)	Complete	IHS DDTP	—
Dr. Grim approved the TLDC charter. (Page 22)	—	—	—
Dr. Acton will set up a briefing call or meeting time to discuss grants management issues with Dr. Grim and the IHS DGO. (Page 22)	Ongoing	Dr. Acton	
The IHS OIT will provide the IHS DDTP and TLDC with annual reports on the diabetes data funds. (Page 25)	Ongoing	IHS OIT	
The IHS DDTP will distribute copies of a draft TLDC orientation binder for their review at an upcoming TLDC meeting. The IHS DDTP will send a copy of the draft binder to H. Sally Smith. (Page 26)	September 14–15, 2006	IHS DDTP	Althea Tortalita-Cajero will bring a copy for TLDC members to review.
The IHS DDTP needs to provide TLDC members with copies of the NPAIHB letter signed by Linda Holt regarding SDPI data ownership issues. (Page 26)	September 14–15, 2006	IHS DDTP	Althea Tortalita-Cajero will make copies for TLDC members.

Ongoing Action Items

Ongoing Action Item	Timeline	Person Responsible	Notes
The IHS DDTP will provide the TLDC with the FY 05 data funds report as soon as it is available from the IHS OIT.	Ongoing	IHS DDTP	Lorraine Valdez
A TLDC member recommended that the advocacy packets include information on diabetes data and TLDC projects, such as the *Eagle Books* and Diabetes Education in Tribal Schools Project.	Ongoing	IHS DDTP	—
A TLDC member requested information on important people to contact for advocacy efforts and lists of relevant committee members.	Ongoing	TLDC co-chairs	—
The IHS DDTP will share the updated Standards of Care for Diabetes as soon as they are complete.	Ongoing	IHS DDTP	Althea Tortalita-Cajero will make copies for TLDC members.
A TLDC member recommended that the TLDC establish a program to develop a resource library.	To be determined	To be determined	—
The IHS DDTP will share the final DHHS report on their SDPI review with the TLDC when it becomes available.	Ongoing	IHS DDTP	Lois Hodge and Dr. Acton
The TLDC should provide recommendations to the IHS DDTP on what to do if grantees do not perform.	Ongoing	TLDC and IHS DDTP	—
A TLDC member requested that the TLDC receive regular status reports on the grantees and a summary of the progress and financial reports required of the grantees.	Quarterly at TLDC meetings	IHS DDTP	—
The TLDC should consider expressing to Dr. Grim that: (1) the IHS DGO should focus on grants processing, not training; and (2) money should be set aside to allow national or regional tribal organizations or tribes to provide training and technical assistance.	To be determined	TLDC	Agenda item for September 2006 TLDC meeting

Tribal Leaders Diabetes Committee Meeting
Meeting Summary

Day 1: April 27, 2006

Subject	Discussion	Action
Welcome, introductions, and review of agenda Motion carried to approve the TLDC meeting agenda for April 27–28, 2006	**Day One—Thursday, April 27, 2006** **Meeting called to order at 8:45 a.m.** – Mr. Rolin, Tribal co-chair, welcomed the TLDC members and guests and offered the blessing. – Asked TLDC members and guests to introduce themselves. – Reviewed meeting agenda and announced Dr. Grim would join the meeting by phone during Day Two. The main purpose of the conference call with Dr. Grim is to discuss finalizing the TLDC charter. Ms. Smith moved to approve the agenda for April 27–28, 2006. Ms. Nelson seconded the motion. The motion carried to approve the TLDC meeting agenda for April 27–28, 2006.	Transcript cross-reference: Pages 9–11
Legislative update IHCIA Senate update IHCIA Congress update Justice Department concerns with the IHCIA IHCIA advocacy activities	Ms. Bohlen from the NIHB, provided an update on the IHCIA reauthorization: – The IHCIA was successfully marked up out of the Senate Committee on Indian Affairs. – In October 2005, the Senate raised several objections. Senator Charles Grassley from Iowa, chair of the Senate Finance Committee, raised objections to cost premiums, co-payments, and other rules under Medicare and Medicaid, as well as objections to special legislative treatment on the basis of ethnicity. – The Senate Democratic Policy Committee devoted one of its weekly meetings to the IHCIA reauthorization. – The Senate Indian Affairs Committee is trying to get the IHCIA out on the Senate floor during the Senate Health Week. – Congressman Young will be the sponsor of the House version of the IHCIA. Congressman Young has assured the NIHB that the bill should get out of committee very quickly without any hearings. – Mr. Rolin indicated that the Justice Department raised concerns on tort claim coverage and urban Indian health programs. – The NIHB has implemented several advocacy activities for the IHCIA. The goal of these advocacy activities is to educate politicians that AI/AN have political status and that AI/AN health is an American issue. The activities include:	Transcript cross-reference: Pages 12–18

Subject	Discussion	Action
IHCIA advocacy activities (continued)	• Senate briefings on sovereignty, history of AI/AN health policy, and history of the relationship with the federal government. • Letter writing campaign with physician organizations, specialty societies, the American Medical Association, allied health professional organizations, and pharmaceutical companies. • IHCIA Coalition conference call scheduled for May 1, 2006. • NIHB- and NCAI-sponsored press conference on May 16 and 17, 2006, in Washington DC. The NIHB has invited Senator Dorgan, Congressman Young, and Senator McCain to speak at this event. Ms. Smith and Lt. Governor Keel will speak at the event.	
FY 07 budget	Ms. Bohlen provided an update on the FY 07 budget: – The President recommended a 4% increase in the IHS budget. However, part of this increase was achieved by redlining the urban Indian health programs. – Response from the NIHB and other organizations: • On February 14, 2006, Ms. Kitcheyan testified before the Senate Committee on Indian Affairs on the budget process and the President's recommendations. • The NIHB recommends a 10% increase in the budget and has testified before the House Appropriations Committee on this matter. The NIHB also recommends national tribal consultation. • The Association of Community Health Centers wrote a letter to the Administration expressing concern about handling and funding for the additional capacity and the ability to provide culturally competent care. – Lt. Governor Keel discussed the need for AI/AN organizations to work collaboratively on legislative and budget issues.	
Past and upcoming meetings	Ms. Bohlen updated the TLDC on past and upcoming meetings: – The NIHB held a crystal methamphetamine hearing and recovery conference with White Bison in Denver. The conference report is forthcoming. – The NIHB and NCAI are co-sponsoring a telehealth conference on May 18, 2006. – The NIHB Annual Consumer Conference will be held in Denver at the Adams Mark Hotel on October 10–13, 2006. – Meetings discussed above: IHCIA Coalition conference call (May 1,	

Subject	Discussion	Action
	2006) and IHCIA press conference (May 16 and 17, 2006).	
SDPI reauthorization meeting Background	The TLDC and attendees discussed the SDPI reauthorization: – Ms. Bohlen requested compelling stories on diabetes from the TLDC and IHS DDTP to be used in an SDPI press-briefing book for the press conference on May 16 and 17, 2006 (see above). – Mr. Rolin and Mr. Strommer noted that the key to success during the 2002 reauthorization process was the strong level of collaboration among AI/AN organizations, non-AI/AN organizations, regional health boards, the NIHB, and tribes. Mr. Rolin expressed the importance of working with organizations, such as the JDRF and ADA, on the SDPI reauthorization.	Transcript cross-reference: Pages 18–25
Stakeholder meeting	Mr. Strommer proposed a stakeholder meeting for the SDPI reauthorization effort on June 14, 2006, in Washington, DC. – The meeting would allow the IHS and NIH to present the government perspective on the SDPI, and offer ideas on useful themes to carry forward in the reauthorization effort. – After the IHS and NIH leave the meeting, the stakeholders can further discuss strategies and identify important issues. – Mr. Strommer suggested that the TLDC send out questionnaires to tribes to indicate that the TLDC is about to start the reauthorization effort and ask what the tribes think of the SDPI, how it has worked, whether they have any suggestions for how it could be improved, and what issues they think the TLDC should focus on as the reauthorization process progresses. – The TLDC agreed on the June 14 stakeholder meeting, and scheduled a tribal leaders meeting for June 13.	
Carryover of SDPI funds	TLDC discussion on carryover of SDPI funds: – Mr. Nakai raised concern that SDPI carryover may become a major issue in the SDPI reauthorization effort. – Dr. Acton noted that carryover is not a new issue. The SDPI grantees have been working to learn new DHHS grant regulations. With continued technical assistance, Dr. Acton expects carryover issues to improve in the future.	
ADA "Awakening the Spirit" Campaign	Dr. Roubideaux, chair of the "Awakening the Spirit Campaign" for the ADA, updated the TLDC on the campaign's role in advocating for the SDPI reauthorization: – Ms. Montez, with the ADA government advocacy department, met with the Senate Committee on Indian Affairs in November. She was told that they did not want to begin work on the SDPI reauthorization because they were working on the IHCIA, but would take direction	

Subject	Discussion	Action
ADA advocacy kit for the SDPI Novo Nordisk involvement Motion carried to work in partnership with the ADA on the SDPI reauthorization, and include the ADA advocacy packet on the next TLDC meeting agenda Motion carried for the TLDC to attend meetings on the SDPI reauthorization in Washington, DC	from Mr. Rolin. – The ADA is developing an SDPI advocacy kit. The ADA will cover the costs of the kit and will pay for a press or Congressional briefing on the SDPI reauthorization. The advocacy kit will include the following materials: • Information on why it is important to reauthorize the SDPI. • A general overview of the SDPI and the process for reauthorization. • Success stories from the SDPI. • A DVD on the SDPI. • Sample letters encouraging Congressional representatives to reauthorize the SDPI. • A one-pager on how to work with local ADA offices to generate letter writing campaigns. • Tips for writing to Congress and e-mailing Congress. • A diabetes issue brief and fact sheet. • An overview of the campaign team. • A fact sheet on diabetes in AI/AN. – Dr. Roubideaux will provide the TLDC with a draft of the advocacy kit prior to the next TLDC meeting for their review and input. – Novo Nordisk is willing to sponsor events for the reauthorization. Ms. Smith moved to accept the ADA's offer to work with the TLDC on the SDPI reauthorization effort and include the ADA advocacy kit as an agenda item for the next TLDC meeting. – Dr. Goforth Parker seconded the motion. – The motion carried. Ms. Holt moved for the TLDC attend the tribal leaders meeting on June 13, 2006, and the stakeholders meeting on June 14, 2006. – Dr. Goforth Parker seconded the motion. – The motion carried. **Break at 10:43 a.m.**	Dr. Roubideaux will provide the TLDC with a draft of the SDPI advocacy kit prior to the next TLDC meeting for their review and input (see related comments on next page).

Subject	Discussion	Action
Update on the US/Mexico Indigenous Peoples Roundtable on Diabetes Update on the Chickasaw Nation SDPI program Mexico's interest in prevention and preserving traditional behavior and culture Dr. Grim's presentation Next steps	Mr. Rolin provided an update on the US/Mexico roundtable on diabetes: – Dr. Acton, Dr. Goforth Parker, Dr. Grim, Dr. Tonemah, Dr. Young from the DHHS, and Mr. Rolin traveled to Mexico on March 1, 2006, for the roundtable discussion. – The roundtable discussion originated from a three-country agreement signed by President Bush, President Fox of Mexico, and Prime Minister Martin of Canada that addressed the health disparities affecting indigenous people. Dr. Goforth Parker delivered her presentation from the roundtable discussion to the TLDC. Her presentation included: – Background information on and a historical overview of the Chickasaw Nation and their health care system. – Overview of the Balanced Budget Act, the role of the TLDC, and the SDPI. – Information on the Chickasaw Nation's new diabetes facility, which was funded through grants, special tribal funding, and SDPI funding. – Information on how the Chickasaw Nation has used their SDPI funds, including eye and teeth exams, foot clinics, gestational diabetes programs, exercise equipment, diabetes camps, and a Family Life Center that offers cooking classes and walking programs. – Information on partnerships with the state of Oklahoma and the University of Oklahoma Health Sciences Center. Dr. Acton noted that her roundtable group focused on the emerging epidemic of diabetes among Mexico's indigenous people and their interest in diabetes prevention and preserving traditional behavior and foods. Mr. Rolin reported that Dr. Grim presented on the IHS, tribes, and government-to-government relationship. Mr. Rolin reported that the DHHS will schedule a follow-up meeting and a final report will be available soon.	Transcript cross-reference: Pages 25–29
Presentation by Gale Marshall	Ms. Marshall showed a video presentation on the SDPI to the TLDC. The video included information on the history of the SPDI, interviews with tribal leaders, and stories from SDPI programs. **Break at 12:12 p.m.**	Transcript cross-reference: Pages 29
Update on the SDPI	**Meeting called to order at 1:31 p.m.** Dr. Acton provided an update on the SDPI: – The SDPI began in 1998 with $30 million per year through the	Transcript cross-reference: Pages 29–33

Subject	Discussion	Action
Funding	Balanced Budget Act of 1997. In 2001, Congress increased the funds to $100 million per year. In 2004, the funds increased to $150 million per year through 2008.	
Allocation of funds	– Allocation of funds: • The Areas receive $108.9 million per year through 2008. • $5.2 million per year goes toward strengthening the data infrastructure and the EHR. • The competitive grant program receives $27.4 million per year. • The urban Indian programs receive $7.5 million per year. • The NDWP receives $1 million per year.	
Legislative intent and requirements	– The legislative intent of the SDPI funds is for the prevention and treatment of diabetes. Congress further required the IHS DDTP to use a grants process, conduct an evaluation of the program, use a best practices approach, and build on lessons learned. • The IHS evaluated the SDPI in 2000 and 2004. The 2004 *Report to Congress* on the IHS DDTP website. • The next report to Congress is due in 2007.	
TLDC	– The TLDC was established at the beginning of the SDPI. The TLDC has become an advisory committee to other agencies on issues related to diabetes and its complications, and is now advising the IHS on chronic disease and advocacy issues.	
Diabetes network	– The SDPI diabetes network includes the IHS DDTP office in Albuquerque, 13 ADCs stationed throughout the country who serve as grant project officers and provide technical assistance, 19 Model Diabetes Programs, and 399 grant sites. – The IHS DDTP has a number of efforts aimed at improving communication with the diabetes network, including: • An e-mail listserve of the grantees. • WebX trainings. • Newsletters, which may include a regular column for the TLDC.	
Other SDPI activities	– Other SDPI activities: • The IHS DDTP has updated the best practices, and will share copies of the short and long versions of each best practice with the TLDC at the next meeting. The best practices will also be available on the IHS DDTP website. • The diabetes regional meetings will take place in May (Atlanta) and in September (San Francisco). Because of the low turnout for the May meeting, the IHS DDTP plans to offer	The IHS DDTP will provide copies of the long and short versions of the best practices for each TLDC member at the next TLDC meeting.

Subject	Discussion	Action
Other SDPI activities (continued)	smaller, local meetings rather than larger, regional meetings. • The continuation application kit will come out in June for the non-competitive grant program. • The IHS DDTP is designing the next progress questionnaire for the upcoming report to Congress.	
TLDC concerns about flexibility in grantee budgets	The TLDC raised concern about the lack of flexibility in grantee budgets. Dr. Acton noted: – The IHS DGO requires grantees to write their budget objectives more carefully. – The ADCs are providing the grantees with technical assistance, but the IHS DDTP needs to work with the IHS DGO to identify objectives that are well written and allow for flexibility, and then share them with other grantees for their use.	
SDPI grant issues	Mr. Rolin welcomed Ms. Hodge, who joined the meeting by phone.	Transcript cross-reference: Pages 33–42
Grantee budget objectives	Dr. Acton asked Ms. Hodge how grantees could introduce objectives that were not part of the grantee's original application. Ms. Hodge responded: – If the objective is broad and fits with the original objective, the IHS DGO can allow the expense. Grantees have more flexibility in changing objectives with their continuation applications. – Grantees have less flexibility in changing objectives when they request spending carryover. The carryover must be tied the original goals and objectives of the grantee's application (e.g., a large purchase that has not yet been purchased, or a programmatic objective that has not yet been accomplished).	
Grantees with carryover	Ms. Hodge will provide the TLDC with a list of all grantees with excessive carryover balances at the next TLDC meeting.	The IHS DGO will provide the IHS DDTP with a list of all grantees with excessive carryover balances. The IHS DDTP will share this list with the TLDC at the next TLDC meeting.
Providing instruction on how to write broad objectives	Mr. Nakai suggested that the IHS DDTP provide instruction to the grantees through their ADCs on how to write broad objectives around diabetes prevention and treatment. The ADCs should review and recommend approval of the objective changes to the IHS DGO: – Dr. Acton agreed and suggested that the IHS DDTP also purchase technical assistance and training for the grantees through the NPAIHB or USET. – Dr. Acton noted that grantees also need assistance with grants.gov.	
Funds transfer strategies	For self-governance tribes, Mr. Strommer suggested that SDPI funds be transferred into their self-governance agreements when the SDPI funds are reauthorized. This would allow the tribes to receive the funds in an annual lump sum, and to redesign their programs and reallocate funds as	

Subject	Discussion	Action
Proposed letter to Dr. Grim	necessary. The TLDC recommended that a letter be sent to Dr. Grim, outlining the TLDC's concerns on grants issues, particularly the need for budget flexibility.	The TLDC will submit a letter to Dr. Grim that outlines TLDC concerns on grants issues, particularly the need for budget flexibility.
Update on the CDC NDWP Community-level indicators of change program	Dr. DeBruyn provided an update on the CDC NDWP's program on community-level indicators of change: – The program is the first time that the CDC Division of Diabetes Translation has directly funded tribal programs or tribal organizations. – The CDC NDWP funded eight programs: Hopi Pueblo, United American Indian Involvement, Salish Kootenai College, Lummi Nation, Stockbridge-Munsee Nation, Indian Health Care Resources Center, Southern Ute Tribe, and Ho-Chunk Nation. – The programs receive $100,000 for three years. The first year of the program has been for planning and site visits. – All programs must implement physical activity and nutrition activities, such as walking trails, school menu programs, community gardens, youth sports activities, after school programs, and community advisory groups. – Each program must evaluate its activities, and the CDC NDWP provides evaluation technical assistance.	Transcript cross-reference: Pages 42–44
Update on the *Eagle Books* Press conference Book distribution Future distribution plans	Dr. DeBruyn updated the TLDC on the *Eagle Books*: – The CDC NDWP held a press conference in New Mexico to launch the books. Mr. Rolin was the facilitator for the conference, and the First Lady of New Mexico and the First Lady of the Navajo Nation attended. – Book distribution: • The CDC NDWP has distributed over 150,000 books. • First Book, a non-profit organization, has distributed 200,000 books. • The IHS DDTP will distribute 44,000 books to SDPI grantees and to the Boys and Girls Clubs. • The IHS Head Start Program is distributing one set of books to the 235 Head Start programs. – Future distribution plans: • Print at least 1 million books and 7,000 copies of the teacher and community guide in July 2006.	

Subject	Discussion	Action
Future distribution plans (continued) International interest Motion carried to share Dr. DeBruyn's presentation and the *Eagle Books* with the NDEP	• Put the books on DVDs and CDs. • Develop a mail key to send large quantities of books to tribal organizations. • Include the books when DETS curriculum is sent out. • Find sponsors to print additional copies of the books. – Japan, Canada, Mexico, and Argentina have expressed interest in the books. • The CDC NDWP may explore publishing the book in different languages. • A Japanese film crew met with the CDC NDWP and developed a 45-minute piece on diabetes. • The CDC NDWP will distribute the books at the "Healing Our Spirit Worldwide" conference in August 2006 in Edmonton, Canada. Ms. Smith moved to share Dr. DeBruyn's presentation and the books with the NDEP. – Dr. Goforth Parker seconded the motion. – The motion carried.	
Update on the DETS Program	Dr. Dodge Francis updated the TLDC on the DETS Program. – The DETS Program is a TLDC initiative funded by the IHS, CDC, and NIH. – In June 2006, final drafts of all K–12 units will be ready. The DETS Program plans to beta-test the curriculum in the fall of 2006. – The DETS Program is looking into developing an online format for the curriculum, particularly for high school students. – Dr. Dodge Francis summarized trainings with several sites, including Seminole and Kayenta. Both sites reported very positive results with the curriculum. **Break at 3:35 p.m.**	Transcript cross-reference: Pages 44–46
Update on the SDPI competitive grant program Background on competitive grant program	**Meeting called to order at 3:45 p.m.** Dr. Acton provided an update on the SDPI competitive grant program: – Background on SDPI competitive grant program: • In 2004, Congress directed the IHS to use some of the new SDPI funds to implement a competitive grant program for: (1) the primary prevention of diabetes; and (2) the most	Transcript cross-reference: Pages 46–57

Subject	Discussion	Action
Background on competitive grant program (continued)	compelling complication of diabetes, which is cardiovascular disease. Congress also required that the IHS conduct an evaluation of the program. • The first program is called the Diabetes Prevention Program, which is trying to prevent diabetes in people who are at risk. • The second program is called the Healthy Heart Project, which is trying to prevent cardiovascular disease in people who already have diabetes. • The IHS DDTP developed an RFA, and sites were selected through a DHHS-approved grants process. Thirty-six sites were selected for the Diabetes Prevention Program, and 30 sites were selected for the Healthy Heart Project. • The grantees have completed the planning year. Years 1–3 will be devoted to recruiting participants and using the interventions designed in the planning year. The final year (2009) of the program will be a dissemination year, during which the IHS will share the results of the program and lessons learned with other tribes and programs around the country.	
Program structure	– Program structure • The IHS DDTP administers funds and provides leadership and general oversight on program activities and coordination. • The IHS DGO provides general oversight of the grant administration, conducts financial audits, and monitors financial reports. • The Coordinating Center is responsible for day-to-day coordination and evaluation. They report directly to the IHS DDTP through regular conference calls. Dr. Acton shared the Coordinating Center's contract scope of work with the TLDC. • The Resource Core includes experts who provide technical assistance on an as-needed basis to the grantees.	
Lessons learned during the planning year	– Lessons learned during the planning year: • The IHS DDTP used a collaborative process to encourage active participation among the grantees in making decisions on planning the interventions and evaluation. • Grantees are hiring staff, but the staff turnover rate has been high (approximately 46%). • Communication and technical assistance remain problems because the programs are at different skill levels. • RPMS use is not at the level it should be. • Obtaining tribal and health board approval letters has been difficult.	

Subject	Discussion	Action
Evaluation process	– Evaluation process: • The evaluation will be a comprehensive, multi-component evaluation. Future funding may depend on this evaluation. • Grantees are required to collect and report on specific data, as outlined in the grant's terms and conditions. • The IHS DDTP and the Coordinating Center analyze the data and report the data to the TLDC, IHS senior leadership, and Congress. • Grantees are being trained on handling data and following all confidentiality and data transfer rules.	
Data sharing and ownership	– Data sharing and ownership: • In September 2005, the National IHS IRB determined that the competitive grant program was a public health evaluation and not research. They deemed the program to be in compliance with HIPPA and noted that they did not require further approval by Area IRBs. • If Area IRB approval was locally required, the IHS DDTP instructed the grantees to follow their local rules. • In October and November 2005, two grantees requested data sharing clarification. The IHS DDTP developed a draft data sharing document to negotiate the data sharing agreement between the IHS and grantee. • In December 2005, the Portland Area IHS IRB determined that the program was research, and that the grantees needed to modify their consent forms, clarify the methods, and clarify data ownership and management issues. The Coordinating Center responded to the Portland Area IHS IRB requests for further information on methods and the draft data ownership document. • Dr. Acton noted that the Coordinating Center's binding contract with the federal government specifies that they do not own any data, cannot publish anything without the IHS's explicit permission, and must return all data to the IHS at the end of the program.	
Portland Area concerns regarding access to data and data ownership	The TLDC discussed concerns about data ownership raised by the Portland Area: – Ms. Holt raised concern about a timeline for data destruction. Dr. Acton responded that a timeline for data destruction has not been set. – Ms. Holt noted that agreements with grantees should not include statements of implied consent for publications. • Dr. Acton noted that implied consent is important to ensure	

Subject	Discussion	Action
Portland Area concerns regarding access to data and data ownership (continued)	that the IHS can respond to requests from Congress in a timely manner. She also noted that this issue needs to be addressed on a wider scale because it also affects other programs. • Dr. Roubideaux noted that any reports on the program will include only aggregate data, not data on a specific grantee. Nor will reports name specific tribes. • Mr. Finkbonner noted that the Portland Area tribes passed a resolution saying that the tribes are the owners of their data and any publication requires the written consent of the tribes that participated in the program. Dr. Acton suggested that the Portland Area revise the draft data sharing document to address their concerns. • Mr. Finkbonner also noted that the Portland Area IHS IRB considers the program to be research. Dr. Acton responded that the IHS is taking already-published research and applying it to AI/AN communities. Any publications on the program would address the program's success with applying the research to AI/AN communities. • Dr. Acton noted that, as the granting authority, she must work with the grantees and respond to their requests. The IHS DDTP does not have a formal relationship with the Portland Area IHS IRB. Working with entities other than the grantees is a violation of DHHS grants law. • Dr. Roubideaux noted that Dr. Acton must follow official grants policy and respond to requests from grantees. The grantees from the Portland Area that need clarification on data ownership need to contact Dr. Acton directly on their specific needs. • Mr. Finkbonner suggested a future conference call to work through the issues presented above.	
Other program activities	Other program activities: – The continuation applications are due July 2006. – The IHS DDTP and Coordinating Center are developing a report card to measure grantee performance. **Adjourn at 4:45 p.m. until 8:30 a.m. April 28, 2006**.	

Tribal Leaders Diabetes Committee Meeting
Meeting Summary

Day 2: April 28, 2006

Subject	Discussion	Action
Welcome and announcements	**Day Two—Friday, April 28, 2006** **Meeting called to order at 8:45 a.m.** – Mr. Rolin welcomed the TLDC members and audience and offered the blessing. – Mr. Rolin reviewed the agenda for the upcoming conference call with Dr. Grim.	Transcript cross-reference: Page 58
Review of TLDC meeting summary from February 2006 Motion carried to adopt the TLDC meeting summary from February 15–16, 2006	The TLDC reviewed the meeting summary from the TLDC meeting held February 15–16, 2006. – The TLDC decided to postpone discussion of the action items regarding the IHS chronic disease management initiative and draft TLDC orientation binder pending further information. – Ms. Smith made a motion to adopt the summary of February 15–16, 2006. – Ms. Nelson seconded the motion. **The motion carried to adopt the TLDC meeting summary from February 15–16, 2006**.	Transcript cross-reference: Page 58 A TLDC member requested an update on the IHS chronic disease management initiative and draft TLDC orientation binder at the next TLDC meeting
Upcoming TLDC meetings DHHS meeting review	The TLDC scheduled their third and fourth (final) TLDC meetings of 2006: – Third meeting: September 14–15, 2006, in Washington, DC. (September 13 will be a travel day.) – Fourth meeting: December 7–8, 2006, in San Francisco. (December 6 will be a travel day.) Ms. Nelson indicated that Dawn Phillips will give a presentation at the December meeting. Dr. Action mentioned that the DHHS may require the IHS to cancel some meetings. She will advise the TLDC if the committee will be affected by the meeting cancellations.	Transcript cross-reference: Pages 58–59 Next TLDC meeting will be held September 14–15, 2006, in Washington, DC Fourth TLDC meeting will be held December 7–8, 2006, in San Francisco Dawn Phillips will give a presentation at the December TLDC meeting

Subject	Discussion	Action
Conference call with Dr. Grim Presentation to H. Sally Smith	Dr. Grim joined the TLDC meeting by conference call. Dr. Grim presented a gift to Ms. Smith for her "outstanding service, vision, and leadership on the TLDC" from 1997 to 2006.	Transcript cross-reference: Pages 59–69
Upcoming SDPI reauthorization meeting	Mr. Rolin updated Dr. Grim on an upcoming SDPI reauthorization meeting in Washington, DC: – Tribal leaders meeting on June 13, 2006. – Stakeholders meeting on June 14, 2006. Representatives from the ADA, JDRF, tribal leadership, and others will attend. – Mr. Rolin requested representation from the IHS and DHHS at the stakeholders meeting. **Dr. Acton will notify Dr. Grim's office of the meeting dates**.	The IHS DDTP will need to provide a schedule of upcoming TLDC meeting dates to Dr. Grim's office
Dr. Grim's final approval of the TLDC charter	Dr. Grim and the TLDC discussed the TLDC charter: – Dr. Grim thanked the TLDC for agreeing to expand their scope to include advising him on the chronic disease management initiative. – Dr. Grim agreed with the TLDC that representatives from the national organizations should be non-voting members based on the new consultation policy for the IHS and DHHS, as well as FACA exemption. – Dr. Grim noted that the opinions and perspectives of the representatives from the national organizations should be taken into account when the voting members (i.e., the representatives from the 12 IHS Areas and the federal representative) vote on an issue. – **Dr. Grim agreed to accept the TLDC charter as final**.	Dr. Grim approved the TLDC charter.
SDPI reauthorization	The TLDC discussed the SDPI reauthorization with Dr. Grim: – Dr. Grim recommended pushing for reauthorization in FY 08 instead of FY 09. – Dr. Grim has informed federal staff and AI/AN organizations that the TLDC is working on the reauthorization and will give guidance on how to proceed. – The TLDC will send a letter to Dr. Grim expressing concern about IHS DGO management of the competitive and non-competitive program budgets. **Dr. Acton will set up a briefing call or meeting for Dr. Grim, the IHS DDTP, and the IHS DGO to discuss this issue**. – The TLDC discussed possible mechanisms of transferring SDPI funds through the Interior Committee to improve budget flexibility. The TLDC and IHS would need to review this mechanism for possible adverse risks and outcomes. DHHS review of the SDPI:	Dr. Acton will set up a briefing call or meeting for Dr. Grim, the IHS DDTP, and the IHS DGO to discuss grants management issues.

Subject	Discussion	Action
DHHS review of the SDPI	– Mr. Nakai asked if the IHS has received a report from the DHHS on their review of the SDPI. – Dr. Grim and Dr. Acton informed the TLDC that the report is forthcoming and will be shared when it is available.	
Funding for urban Indian programs	Funding for urban Indian programs: – Mr. Nakai raised concern about the proposed budget cuts that will affect funding for the urban Indian programs. Mr. Nakai was particularly concerned about the high costs associated with tribal members having to travel for health care. – Dr. Grim acknowledged that people may need to travel to receive health care if some clinics close due to budget cuts. He further noted that clinics that receive 50% funding from the IHS would be severely affected. – Dr. Grim noted that the IHS should know by May 5 if the House plans to restore the urban Indian program line item in the budget. – Dr. Grim informed the TLDC that the IHS is working with the urban programs to prepare them in the event that the budget line item is not restored. Dr. Grim also reported that the IHS is conducting a legal analysis on the Title V authorization in the IHCIA for funding urban programs.	
INMED scholarship and loan repayment programs	INMED scholarship and loan repayment programs: – Dr. Goforth Parker expressed concern about funding for the INMED scholarship and loan repayment programs. – Dr. Grim responded that he had not heard of any budget problems with these programs. However, the IHS has been unable to increase the budget for the programs. **Break at 10:15 a.m.**	
Update on the SPDI diabetes data funds	**Meeting called to order at 10:52 a.m.** Dr. Hayes joined the meeting by conference call to update the TLDC on the IHS EHR.	Transcript cross-reference: Pages 69–76
Overview of the EHR	Overview of the EHR (www.ehr.ihs.gov): – The SDPI contributes $5.2 million toward strengthening the data infrastructure of the IHS, including implementation of the EHR. – The EHR consists of an integrated RPMS database enhanced with a GUI, and adapted applications from the VA for specific use by the IHS.	

Subject	Discussion	Action
How the EHR improves care	How EHR improves care: – The EHR provides easier access to information. • A data entry clerk is not required. • The clinician or user enters the information, which is immediately available to all users. – Satellite clinics that use the same RPMS system have immediate access to data (i.e., copying of records is not required). – There is less chance for prescription errors with the EHR computerized order entry system, and the EHR provides complete, up-to-date medication lists. – The EHR automatically checks patients' allergies or medication interactions. – The EHR provides reminders and notifications at the point of care (e.g., reminders for services and interventions, such as A1c tests, mammograms, pap smears, foot screens, and eye exams). – The ERH brings all abnormal lab results to the users' immediate attention.	
EHR milestones	EHR milestones: – The EHR was certified in January 2005. – Seven sites are testing the EHR. – Thus far, the EHR has been implemented at 32 federal and 14 tribal facilities. – All federal facilities will be using the EHR by the end of 2008. – The next EHR version, version 2.0, is currently in development and will be distributed by the end of 2007.	
EHR performance	The EHR has been associated with the following improvements: – Decreased medication errors. – Reduced waiting times for pharmacies. – Improved pneumovax immunizations rates. – Improved documentation for domestic violence, depression, and tobacco use screening. – Improved medication education documentation. – Improved collections and return on investment.	
Costs associated with the EHR	Costs associated with implementing the EHR: – The IHS OIT covers installation, support (typically three site visits), and license costs.	

Subject	Discussion	Action
Costs associated with the EHR (continued)	– Upgraded servers and back-up servers ($20,000–$120,000). – User hardware and workstations ($600–$2,000 per user). – Clinical application coordinator ($80,000 per year). This person provides local training and support for the EHR. – Travel costs related to attending training sessions ($5,000–$15,000). – Median costs reported by sites: • Hospitals: $380,000 • Primary clinics: $135,000 • Satellite clinics: $18,000	
EHR training and support	EHR training and support: – The SDPI funds cover training and support costs. – A team of IHS OIT trainers visits EHR sites and pre-EHR sites for on-site training and technical support. – Four sites offer a one-day overview training, called “Lessons Learned”. – The IHS OIT provides a weeklong training every other month in Albuquerque.	
Area level funds distribution and support	Area level funds distribution and support: – In FY 05, the SDPI provided $2.4 million to the Areas for EHR implementation. The Areas supplemented this amount with an additional $842,000. The total money spent on the EHR in FY 05 was $3.25 million. – Most funds were spent on hardware (e.g., servers, upgraded networks, and user hardware). – IT staff at the Areas are responsible for providing assistance to sites on hardware and networks. Area-level clinical application coordinators support and assist the coordinators at the sites, as well as provide direct service to small sites. – Every Area made progress on EHR implementation and improvement of IT infrastructure. Areas that require more help in the EHR implementation will receive a higher proportion of Area funds for FY 06.	
Cost reports	The IHS OIT will begin providing the IHS DDTP and TLDC with annual cost reports, beginning with a report for FY 05.	The IHS OIT will provide the IHS DDTP and TLDC with annual reports on the diabetes data funds.
Update on the urban Indian program	Ms. Wolf updated the TLDC on the urban Indian program: – She reported on recent site visits to a residential treatment center in Portland, Oregon, and a program Pierre, South Dakota.	Transcript cross-reference: Pages 76–78

Subject	Discussion	Action
Update on the urban Indian program (continued)	– The urban programs will report on all 17 GPRA measures, including seven diabetes measures for the period of July 1, 2005–June 30, 2006. – Four programs have been removed from the DHHS alert list. – The IHS needs to outline steps to take in case urban Indian health programs close as a result of budget cuts.	
Meeting wrap-up	Dr. Acton indicated that the IHS DDTP would distribute copies of a draft TLDC orientation binder for their review at an upcoming TLDC meeting. The IHS DDTP will send a copy of the draft binder to H. Sally Smith. Ms. Holt requested that the NPAIHB letter regarding SDPI data ownership issues and concerns be sent to all TLDC members. Ms. Bohlen noted that special funding discussion would be on the agenda for the next budget consultation meeting. Ms. Smith and Ms. Holt motioned for the meeting to be adjourned. The motion carried, and Mr. Rolin gave the closing prayer. **Meeting adjourned at 11:58 a.m.**	Transcript cross-reference: Pages 78–79 The IHS DDTP will distribute copies of a draft TLDC orientation binder for their review at an upcoming TLDC meeting. The IHS DDTP will send a copy of the draft binder to H. Sally Smith. The IHS DDTP needs to provide TLDC members with copies of the NPAIHB letter regarding SDPI data ownership issues.